

**People Leading Accessible Networks of Support (PLANS)  
Statewide Workgroup  
Governor's Inn  
Pierre, SD  
March 16-17, 2004**

**CALL TO ORDER**

Brooke Lusk called the meeting to order at 1:00 p.m. Tuesday.



Members Present were:

Clint Waara  
Vicky Day  
Dawn Kellogg  
Cindy Taber  
Kristi Heumiller  
Tim Neyhart  
Sharon Sonnenschein

Kirby Mellegard  
Brenda Smith  
Dan Spotted Eagle  
Anne Rieck McFarland  
Beth Hosek  
Michelle Powers

Renee Osborne  
Mary Funge  
Travis Arneson  
Shirley Sterling  
Ted Williams  
Ronda Williams

Others Present were:

Brooke Lusk  
Donna Olivier

Lisa Lunstra

Wanda Seiler



**PLANS project Overview – Brooke Lusk. Refer to handout in binder.**



- Funding from US Dept of Health and Human Services, Administration on Developmental Disabilities - Projects of National Significance - Family Support 360.
- Grant period is 9/29/03 through 9/30/04 and for planning activities only.
- ADD informed projects that there will be a competitive request for proposals (RFP) in the near future for 3 year implementation grants.

- ADD funded projects that promoted the economic and social well-being of families, children, individuals and communities; empowered families and individuals to increase their own economic independence and productivity and strong, healthy, supportive communities; partnerships with individuals, frontline service providers, and communities; services that are planned and integrated to improve access to programs and supports to individuals; and a real community based approach.
- Other key points that ADD was looking for was an innovative strategy and a model process that can be replicated.
- The purpose of all 31 projects are multi-agency partnerships to design a One-Stop Center.
- The One-Stop Center should assist families with a child or adult member with a disability, to preserve, strengthen and maintain the family unit.

Question: Does ADD require any co-funding or matching payment from the State?

Answer: The state received \$100,000 worth of federal funds and the state has matched that with \$33,334 of state funding.

- Seamless single point of entry service delivery model. Listening to parents comment about all the different programs, people, forms and eligibility requirements. Wouldn't it be nice if there was one person or maybe two that they could contact to get the majority of their answers?
- Workgroup will provide direction for the One Stop- could be a person, place, or website, DVD, etc.



- Single point of entry should be family-centered and family-directed.
- Families have the greatest possible decision making ability and control regarding the use of the services and support for their family member with disabilities.
- Supports are endless depending on what someone may need to achieve their outcomes in life. i.e. accessible transportation, accessible housing, mental health services, job training, employment with reasonable accommodations
- Target area is the 8 rural counties around Codington County. (Grant, Roberts, Marshall, Day, Spink, Clark, Hamlin and Deuel)
- Reasons why this area was chosen: rural, Sisseton-Wahpeton tribe, GRDDSS, Empowerment Zone (will try to bring someone in from BASEC to talk about what services they offer).



- GRDDSS is a grassroots parent advocacy group. Parents have identified services and supports that their children need to remain in Milbank or other communities. They went through an interview process and have been working with ATCO in Watertown to provide services. There are now three and a half staff in Grant/Roberts counties providing services to individuals in their community.



- Implementation Plan is the meat of the project - the who, what, where, when and why! This is what we need to give to ADD when the project is done and say, "This is what we want to implement in SD."
- A formal needs assessment has been completed - National Core Indicators. The assessment shows a very high level of satisfaction with services but below average satisfaction for choice and control of services. Survey of people receiving services from the Home and Community Based Services (HCBS) waiver and the Family Support (FS) waiver. Input will also be gathered from public forums on an informal basis.



- Legal analysis will look at various funding streams, legal and policy barriers, and eligibility criteria and how these will impact the implementation plan.
- Training Needs of staff who will be working in the single point of entry system and also training needs of non-staff that might be working with individuals in the community.
- Possible website to include existing local and state resources. Putting all of the resource directories in one place.

Question: The first year is the planning year. If we don't get the three year implementation grant, then what happens to our plan?

Answer: Depends on what the plan does. If we have limited funds for the plan, then we have to prioritize and make the best out of what resources we have. To move forward with the PLANS grant, we have a match. We would have to have a match to do that. We are really optimistic and see SD as a state as very competitive on the forefront with this project because of the goals as well as the pilot area we have chosen. A lot of the grants have standardized points that are given

and we have positioned ourselves very well. We have competed for three grants in the last three years that were funded. Our state was in the top two for recipients for grants out of about 100 grants sent.

- In April two of us will attend a technical assistance meeting to find out more about the RFP for the three year grant and information about what other states are doing with their grants.

### **Responsibilities of Workgroup members – Brooke Lusk. Refer to handout in binder.**

- Attend meetings.
- Be prepared for the meetings in advance.
- Discussion on the different learning and communication styles.
- Reasons you were chosen to be on the workgroup -you are respected and your opinion is valued.

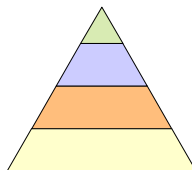


- Make sure that everybody is involved - everyone will be given the opportunity to speak, but if you want to pass you may.
- Actively listen to what the other workgroup members have to say.



- Ask questions - if you don't feel comfortable asking in front of the group, please ask the question later.
- Workgroup role is to help build guiding principles for a seamless single point of entry service delivery model.
- Assist the Project Coordinators in writing the implementation plan.
- Fill out reimbursement forms.
- Have fun! We are all passionate about these issues and we think we can have a lot of fun with this group.

### **Self-Advocacy and participation during workgroups – Tim Neyhart**



The \$25,000 Pyramid Game

- What are the building blocks of an effective workgroup?
- A pyramid is built on a base.

- Information/Resources, Goals, Consensus, Shared Responsibility, Mutual Growth, Equality
- Communication styles using I vs. You messages.
- Natural Communication Style – “I” messages. Tim spoke about using messages and interaction.
- Practice using examples. Use “I” messages. Ex. I feel frustrated. What is your response?
- Want - It is ok to say you don't like something. Articulate



- Caution – Be careful what you ask for, because you might get it.
- Observations, Feelings, Thoughts...
- Expectation – What can you do to make me want to do this/be here/ participate/etc.

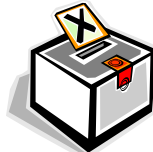
## Break

Cindy Taber and Beth Hosek joined the meeting.

**Parliamentary Procedure – Clint Waara . Refer to handout in binder.**



- Parliamentary Procedure will bring order to the meetings.
- Respect other's opinions.
- Be polite to everyone.
- It is okay to disagree about issues. It isn't personal. Don't get upset about what other people say. Everyone has the right to speak and be heard.
- Identify issues singularly.
- Respect the rights of the minority and everyone else.
- Speak up! Silence will be taken as a sign of approval.
- The meeting will be called to order by Clint.



- A minimum number of voting members must be present. This is called a quorum.
- Minutes of the previous meeting will be read.
- Reports will be made from the officers and committees. An agenda will be prepared, so everybody who has a report to give

will be given time. It will be your duty to listen, take notes and catalogue any questions that you may want answered.

- Unfinished business – this is business from the last meeting that has been delegated out and we are going to listen about those topics or anything we put forth until the next meeting.
- New business
- Announcements
- Call the meeting to close.
- There will be times we have to make a decision. Someone will have to make a motion at that time. A call to action will be given. For example, “I make a motion that....” In order to make a motion, you need to ask the chairperson’s permission to speak. The chairperson will then tell you that you have the floor.
- Someone needs to “second” the motion after the initial motion has been stated. For ex. “I second the motion.”
- Once the motion is read and seconded, the chairperson will re-read the motion to the membership and then that membership will debate the topic.



- After discussion, then the chairperson asks for the vote. At that time then the vote will be taken by Aye’s and Nay’s. A roll call vote will be taken if the vote cannot be determined by Aye’s and Nay’s.
- Amendments – amendments can be made to motions. Ex. “I would like to make an amendment to the motion.” You can also strike the motion, etc. Everything needs seconded and then voted upon.

## **Division of Developmental Disabilities Overview - Wanda Seiler.**

**Refer to handouts.**



- Overview of the structure and organizational chart of the Division of Developmental Disabilities.
- The primary function for DD is to provide funding for services for people with developmental disabilities.
- The second responsibility is to continually ensure that services are developed for people’s needs.
- DD is part of the Department of Human Services (DHS) as a community-based division.
- DHS has two institutions: The Human Services Center in Yankton and the SD Developmental Center in Redfield.



- There are two sources of funding: State general funds – these are your tax dollars. Sales tax is the primary source of revenue. Federal funds – come from the federal government. We have to be accountable to the federal government for our federal dollars.
- Guardianship Program – 100% general funds. No federal funds involved with this program. This is for people who are unable to make decisions on their own. DHS is guardian for approximately 200 people with developmental disabilities. Guardian representatives advise the state staff on matters concerning the best interests of the disabled person.
- HCBS waiver is a federally funded program. The participation is Federal Medical Assistance Percentage (FMAP). \$2 federal funds match \$1 of state funds.



- Family and Community Support – currently funding this service with a federal grant. 75% federal to 25% state ratio for funding stream.
- Adult Foster Care – program that provides support to people with developmental disabilities. Serves approximately 15 people. We spend approximately \$50,000 total per year.
- Community Training Services (CTS) – service provided through contracts with 15 adjustment training centers. This is for people who do not need the intense services offered through some of the other programs. It provides pre-vocational services, independent living skills. We serve about 300 people annually at a cost of about 1.5 million. Annual expenditure is approximately \$5000/person/yr. No federal funds involved.
- Family Support –The purpose of family support is so families are not forced to move from their home communities to get the support and services they need to ensure that the child can be raised in their family home. A waiver funds a great portion of these services. The annual budget runs about 1.8 million. There are 12 local programs with each program having a family support coordinator. We also have a statewide family support program this one has the longest waiting list.
- We are piloting an adult family support program (Family and Community Support listed above). Whether you are a child or an adult, you shouldn't have to move to receive these services. Ex: A young man in Mobridge who has lived with his mother in the family home his whole life. When she went into the nursing

home, he was still in the family home. He would have had to travel 100 miles to an adjustment training center for services. Luckily for him, he had nosy neighbors on both sides that kind of kept an eye on him. Had he moved to an adjustment services, the cost to us would have been very expensive. By allowing him to remain in Mobridge and providing him with services from the Adult Family Support Program we are only spending about \$2000.

- Beth and Cindy talked about what they do through the Adult Family Support Program.

### **Home and Community Based Services (HCBS) waiver – Carol Ruen.** **Refer to handout.**

- Explanation of the institution and the legislation and name changes since 1899.
- Actually a register of people with mental retardation to prevent them from getting married.



- The institution in Redfield was designed as though it were a separate community.
- Population at the high end was 1,200 and now is around 170. Those individuals currently served at the institution have intense behavior needs in addition to developmental disabilities.
- Then in 1960, a few Adjustment Training Centers were started to offer options in the community but people were expected to move to one of the locations.
- In 1981 HCBS was started – also called Katie Beckett waivers after the child whose parents fought for benefits to serve their child at home.
- HCBS provides an alternative to institutional care.
- Waivers are optional and there is no limit to the number a State may operate. Approval of waivers from CMS.
- SD has 4 waivers: Adult Services & Aging, Assistive Daily Living Services (ADLS), Family Support and DD.
- Services available through HCBS are: service coordination, habilitation, nursing, medical equipment, drugs and supplies and other medically-related services.
- There are 19 Adjustment Training Centers statewide that provide these services to individuals.



**Statewide and Local Family Support Programs – Ian Paul, Donna Olivier and Kristi Heumiller. Refer to handouts.**



- Currently serving 540 children on Local Family Support program.
- 381 are on family support waiver.
- 119 served through general funds.
- 12 programs throughout the state.
- Family support coordinator – each family has one that supports the family.
- 45-50 families per coordinator
- Examples of services: incontinent supplies, respiratory care, family support, etc.
- Limited funds
- \$2800/person average. Families may get a different amount depending on their needs.
- Family Support Coordinators get a referral and then go visit the family.
- Involve the whole family and the child in the process.
- Companion Care – mostly teenagers
- Income: accessing services. Contact by phone or email.
- Statewide Family Support program is supporting 219 children at this time with different services.

Question: What kind of services do you provide that are different?

Donna's answer: We pursue the school resources first. We assist with: Diaper, meds, recreational options, therapy, horseback riding, and modifications to home, counseling, etc.

**Benefits Planning Assistance and Outreach - Alia Stowers**



- Benefits planning
- Lot of success stories.
- Work Incentives are available when receiving SSI.
- Many beneficiaries aren't aware of the different options.
- This position doesn't find people jobs.
- Do benefit analyses to inform individuals how their benefits are affected by them returning to work.
- Questions dealing with Social Security appropriate to ask.

Question: Are you paid by BHSS, by the State, by SSI, who pays you?  
Answer: BHSS received a grant from SSI and that pays my salary.

Question: There is a woman in Sioux Falls, right? Don't you kind of work with each other?

Answer: Yes, Vicki Nisich. People living in the Sioux Falls and Brookings area, who are receiving services from VR is who she works with. Most states have several representatives, but our state only has two. PASS program which sometimes can help you start a businesses or purchase items you may need.

Question: If it was just you alone, would these both be under the same program?

Answer: I don't know. We are both trained by Social Security, and we attended the same training. She covers a little smaller area. Population wise it isn't smaller. We sort of do our own things. We do try to work together as often as we can.

Question: Usually when I have questions, I just call Social Security. I am wondering why they don't refer me to you. Do they know your office?

Answer: They are supposed to refer you to me. So far I have met with a lot of cooperation from the reps, but I think a lot of times they don't refer you to me. They are trying to answer the questions themselves. When it comes to certain individual work incentives, or very specific details, I've found that some reps are more knowledgeable in some areas then in others, so in those cases it probably would have been more beneficial for them to just answer the questions. There have been times that we have had to remind them of the federal regulations. This happens sometimes with all the programs.

### **People First Language-Brooke Lusk. Refer to handout in binder**



- Disability Rights Movements began in early 1970's
- 1990-the Senate subcommittee on the Handicap became the Senate Subcommittee on Disability Policy
- 1990 Americans with Disabilities Act was established, prohibiting discrimination based on disability in public service, transportation, employment, public accommodations and telecommunications.
- Late 1990 – Education of all Handicapped Children Act was reauthorized and renamed to Individuals with Disabilities Education Act (IDEA).

- People with a disabilities are valuable people in our community
- Focus on the individual
- Try to avoid using emotions when describing a person's disability
- Be accurate when describing disabilities. It isn't a disease.

Copies of Abstract and a Work Plan were passed out. Please review for strategic planning session tomorrow.

## **Day 2 – Wednesday, March 17, 2004**

### **Review of PLANS grant – Brooke Lusk**


#### **Overview of Target Area – Lisa Lunstra**

- Lisa and Brooke will be attending monthly meetings of the GRDDSS parent workgroup to listen to their needs and ideas.
- At the GRDDSS March meeting there were several presentations including: PLANS, GRDDSS, SD Advocacy, BPAO, Transition, ATCO, Family Support and Resource Coordinator.
- Renee Osborne explained the history of the GRDDSS.

### **National Core Indicators project (NCI) – Brooke Lusk**

- Four surveys were completed
- The first three were family member/guardian who have a child/adult receiving services from HCBS waiver or the individuals themselves. The fourth survey was completed by parents who have a child receiving services from the Family Support waiver.
- Nationally, the project goal is to support state developmental disabilities authorities and support efforts to improve service delivery system.



-  Consumer Outcome Survey - 17 states and one CA County completed survey. Based on individuals receiving services from an adjustment training center. These were done in an interview format. The highest level of satisfaction in this survey came in the areas where they live, access to quality services & service coordination and increase of dignity and respect. This can be used for comparing the states to each other.
- Family Guardian Survey - Individuals who have an adult family member who receives services from an ATC. Nine states and 1 CA County completed the survey. Highest marks in treating people respectfully, efficacy of planning services, quality of service coordination, provision of necessary services, provision of services

in healthy and safe environments, access to community activities, resolution of complaints and grievances, and overall satisfaction. South Dakota received below average marks in the area of choice and consumer control over services.

- Adult Family Survey – 14 states and one CA County. Adults with disabilities living in the family home. SD ranked above average for information and planning, access and delivery of services. Below average in area of choice and control.
- The Child Family survey – 6 states and one CA County. Parents with a child receiving Family Support waiver services. SD had 1<sup>st</sup> place rating overall but below average in the area of choice and control.

### **Adjustment Training Centers overview – Anne Rieck McFarland**



- Sioux Vocational Services mission statement: We find innovative ways for people with disabilities to achieve their dreams.
- Independence and respect are the focus.
- Response to needs
- Range of what we offer
- Beliefs: Value, Dignity, Choice, Facilitating services
- Principles: Honest, Forthcoming, Open, Variety of services
- Hopes and Dreams

Question: If you are a person with disabilities, and you have been success in a job for ten years, you still work there and your abilities are changing, can you get vocational rehabilitation at that job?

Answer: They have to have permanent functional limitations in order to qualify for services. Medical records from the doctor are required.

### **Medicaid - Sharon Sonnenschein**

- Director, Division of Economic Assistance, Dept of Social Services
- Several Benefit programs: financial assistance and medical assistance.



- Medicaid is the largest program and reaches largest number of people.
- Currently 92,000 people receive services on the Medicaid program.

- Bottomline budget in SD: \$600 million.
- Federal Medicaid est. in 1965.
- Largest singly publicly funded health program in the country.
- Eligibility for Medicaid is primarily a means-test.
- SD has 40 different medical programs.
- Caseworkers will fit you into the program you belong.
- SSI program recipients automatically get Medicaid coverage.
- CHIP program - Child Health Insurance Program- one of the newest programs.
- Since 1998, our total program has increased in numbers by 50%.
- You have assistance when you walk into a local social services office. They will find the correct program for you!
- Program for pregnant women helps women who don't have insurance. Once qualified you stay qualified for that pregnancy.
- Low income families program -excluded resources: house, vehicle.
- Transitional medical coverage for 12 months
- Refugee Medical Assistance Program - largest area in Sioux Falls
- Foster care Medical Program - fairly new program. Foster children are eligible for Medicaid. Children in correctional facilities are covered.
- Long-term care - Medical Coverage for individuals who live in medical facilities. Over 4000 living in nursing homes. The cost is very big. Income limit three times greater than SSI limit.
- Over 61,000 children in Medicaid program
- 31,000 adults in Medicaid program
- Ask questions - We want to assist you!

Question: 92,000 from our state's population. Is that comparable to other states?

Answer: Yes. Based on population and depends on the state. We are about the same. Every state governs its' own Medicaid program. Mandated services and groups. How broad is the state? Think about when comparing the states.

Question: If the person has any specific questions, which number is the best to call?

Answer: With the child health insurance program, we were strongly encouraged to have a 800 number. Several agencies are together on that 800 number. You will be referred to the correct department. The complicating piece is what's the question. If I am a recipient and I want to know why I am still being billed by my provider, then that is really a question that goes to Medical Services. I don't understand why I am not eligible? The best solution is to go to your local office. Department of Social Services. If doesn't work then call 773-4678. Or use 800 number and request that someone return your call.

Question: Providers that sign up and agree, established, if there is some problems with providers linking etc.

Answer: Our department is very comfortable with the providers of Medicaid. Comes up with the dental coverage. We contract with Delta Dental to provide the dental services. The community health facilities sometimes employ their own dentists now. There are still problems, but we are finding solutions.

Question: Is everybody considered managed care on Medicaid and SSI?

Answer: You can be on both SSI and Medicaid. You are not considered to be managed care.

Question: You are in the qualifying department, right?

Answer: Yes, eligibility

Question: How many separate forms are there?

Answer: There are a lot of them. Food stamps for example.

### **Vocational Rehabilitation – Ronda Williams. Refer to brochures.**



- Provide services for employment - 5 Regional offices.
- Anyone on SSI/SSDI is automatically eligible.
- Person must be determined eligible within 60 days of application. Once eligible, person makes informed choices about finding a job, what services they want and who they want to help.
- An Individualized Plan for Employment (IPE) is developed for everyone.
- Once employed, 90 days on the job is considered a successful closure.
- Assistive technology is available for work adaptations.
- Project Skills in cooperation with the Office of Special Education is available to youth 16-21 years. VR will pay student's salary up to 250 hours per school year plus workman's compensation.
- SBVI is a separate division for those who are blind or visually impaired.

Question: If someone has been employed, can VR help them find a job if they don't want to work.

Answer: Yes, if they are motivated to work.

Question: If someone went to vocational school and needed assistance finding a job can VR do that now? I know a while back VR was knowledgeable about finding jobs in these fields.

Answer: VR Counselor are mandated to receiving training and education on finding people jobs.

Question: Person has a job but would like a new job because he's bored and his physical abilities can VR help with that?

Answer: He might or might not qualify. It depends on the situation.

**PATH Map - Strategic Planning – Dan Rounds. Refer to copy of PATH map.**



**Closing Remarks – Brooke Lusk**

- We will spend more time on Strategic Planning at the next meeting
- Will try to bring back information from Technical Assistance Conference in Washington D.C.
- We will look at options for hotels and make arrangements. Email will be sent out to members to save the date and minutes will be sent.

**Next meeting date: May 3 and 4 - Chamberlain**